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Person-Centered Planning



A Guide for Families of Individuals
With Developmental Disabilities



Northeast Alberta Community Board
Persons with Developmental Disabilities
Building on community strengths

How this Guide was Developed

Person-Centered Planning was developed by the Northeast Alberta Community Board for Persons with Developmental Disabilities, with assistance from the Alberta Association for Community Living (AACL). Individuals and families from the Northeast Region shared their experiences so other families would be better informed about how planning can contribute to a good life.

Acknowledgements

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The Desjardins Family
Mark Tremblay
The Mackin Family
The Diatel Family
Gordon Draves
Duane Bird

These stories can also be accessed through the web site, NorthEast Community Online, at www.ne-community.com

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The term “son or daughter” is used throughout this booklet. However, the information applies to other family members or close friends of individuals with developmental disabilities.

About this Guide

If someone in your family has a developmental disability, particularly if they have reached or are approaching adulthood, *Person-Centered Planning* is for you. This interactive, multimedia resource, which consists of this booklet and a CD-ROM, introduces the process of Person-Centered Planning. By following this process, you can help your family member get the life they want.

This is a resource for family members. Mothers and fathers, brothers and sisters, and close friends and allies of adults with developmental disabilities can benefit from the information presented in this resource. These people are instrumental in the Person-Centered Planning process. They are the ones who know the individual best, and their input is critical to the success of the plan. Moreover, their ongoing commitment is needed to enable their family member's plan to unfold and their dreams to be realized.

As you work your way through this booklet, you will learn what Person-Centered Planning is, how it can be done, and what it can do for your son or daughter with a developmental disability, as well as for yourself and the rest of your family. Stories of other families are presented so you can learn from their experience with Person-Centered Planning and the results they have achieved.

The Northeast Alberta Community Board for Persons with Developmental Disabilities is pleased to present this resource, *Person-Centered Planning*. The Board recognizes the importance of Person-Centered Planning and strongly recommends it as the foundation for developing shorter-term Individual Service Plans, which are used for planning services and funding.

Our Board's motto is “Building on Community Strengths.” People like you and families like yours are our community's strengths. Through you, we work to achieve our vision: “An Alberta that honours and respects the dignity and equal worth of persons with developmental disabilities.” We welcome you to our community and trust that this resource meets your needs.

How to Use this Guide

Person-Centered Planning is a multimedia resource consisting of this booklet and a CD-ROM. Each of these components can stand alone, or they can be used together as a tool to assist your family as you work through the Person-Centered Planning process.

The CD-ROM presents the same information contained in this booklet, but does so in an interactive, audio format. This form of presentation may be more suited for those who find reading difficult or for those who wish to receive the information in another way. The information contained in the booklet is presented in a print format and is intended to be used as a workbook. As you read through the various sections of the booklet, you will encounter "Questions to Consider," and a space to write your answers or jot down notes.

Used separately or together, the CD-ROM and the booklet will guide you through the Person-Centered Planning process. Step by step, you and your family can plan together, so that your son or daughter with a developmental disability can live the life they want.

Funding Manual

The Northeast Alberta Community Board for Persons with Developmental Difficulties has also developed another multimedia resource, "Understanding Your Funding Options: A Guide for Families of Individuals with Developmental Disabilities." You may find this additional resource helpful when making plans with your family member.



Part 1. About Planning

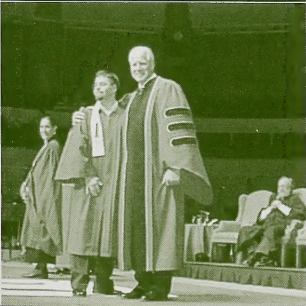
Certainly planning is not restricted to families of individuals with a developmental disability. All families plan in various ways. For example, they may plan a special event like a wedding or family reunion. Changes require planning. For example, caring for a new baby or moving to a new house requires planning.

A crisis often provides motivation for planning. Dealing with an illness, a serious accident, or a sudden death may cause a family to come together and engage in planning of various kinds.

Basically, planning is something that everyone does. We all know that things are more likely to go the way we want them to when we plan. Person-Centered Planning is well worth the effort – we are more able to get the life we want when we plan it. And when someone has a developmental disability, planning is a necessity, as supports may be required to ensure the individual gets to live the life they (and their family) wants.

In Person-Centered Planning, your son or daughter, with the support of their family and others close to them, develops a plan about what they want in their life. They are at the center of the process – they steer and set the direction. That way their plan is designed to get to the results they want, and to go where they want to go. For example, in Person-Centered Planning, things like where to live and with whom, what kind of work to do, whether to pursue post-secondary education, and what to do in their spare time are all things that your son or daughter (along with the family) decides.

In Person-Centered Planning, your son or daughter, with the support of their family and others close to them, develops a plan about what they want in their life.



Questions to Consider

1. Think of a time when your family was involved in a successful planning venture. What do you think contributed to its success?
2. Recall a time when something your family was planning did not turn out well. What do you think accounted for its lack of success? What could you have done differently?

Stories – A Look at Possibilities

The stories in this resource show possibilities – they exemplify what individuals with developmental disabilities can achieve and the lives they can lead. While not all of the stories involve Person-Centered Planning, they may provide some ideas for the planning you engage in with your son or daughter.

The power of planning is evident in the story “Meet the Desjardins.” When Donna Desjardins gave birth to a son with Down Syndrome 26 years ago, she was advised to place him in an institution. Today her son runs his own business, has gone to college, and lives in his own apartment. Here is their story.



Meet the Desjardins

"Daniel was not only raised by us as a family, he was raised by the entire community of St. Paul."

Daniel Desjardins

A number of years ago, the Desjardins returned from a family vacation and found that their house had been broken into and vandalized. As a result of this experience, Daniel discovered that he had a goal - He wanted to make people feel safe. In 1999, with the assistance of the College Connection Program, Daniel became the first person with a developmental disability to enrol in the Police and Security Program at Grant MacEwan Community College in Edmonton.

Like any child leaving home for the first time, Daniel was a bit nervous moving to the "big city." The transition was made easier, however, when Daniel's older brother Rob and his wife Lorraine asked him to live with them while attending college. They were grateful when he accepted their offer. Daniel's eyes light up when he talks about his "Edmonton family" and how his "sister" is both his piano teacher and his "best friend."

Attending college has helped give Daniel confidence in his work abilities. In his last year of college his field placement assignment involved working security on campus. It was his job to patrol buildings, hallways, offices, the cafeteria, and the library to make sure they were safe. He wore a radio strapped to his belt and a uniform while making his rounds. In Daniel's own words, "I really looked professional." When Daniel graduated

from College with the rest of his class, the President of the college shook his hand and turned to the audience to announce that: "We've all been very fortunate to have Daniel in our college, and we have learned much from this young man".

Daniel is an optimistic person who enjoys life fully and deals with his disability as best he can. In his words, "Down Syndrome sucks." He is presently taking psychology courses from the University of Alberta (at Blue Quill College). He lives in his own apartment, drives his Moped to work at the local movie theatre, and is growing his own security business (called DSS Support Network Ltd.) in St. Paul. His web site address is www.dss.pwac.net.

Rob Desjardins

Rob Desjardins was nine years old when his brother was born. When his parents told him that his little brother might have Down Syndrome, Rob remembers hoping that Daniel did have Downs because his parents made it sound so special. Twenty-three years later, Rob and his brother still have a special relationship.

Rob is a soft-spoken and articulate man. He is also shy, and because of this quality, he admits that having a brother with Down's has at times been a challenge. "People with Down's take longer to learn appropriate social skills," he explains. "And they often miss or don't understand proper social cues." For example, Rob laughs as he tells the story of Daniel sitting on a bus, listening to his Walkman, and singing loudly along.

Rob has witnessed firsthand the benefits of Daniel's integration in a regular college setting. Daniel's vocabulary and conversation skills have improved dramatically, and he handles social situations much better. "Daniel is most likely to miss social cues when he is tired," Rob explains. "But when he's on," Rob says, smiling, "he can be so eloquent. He's like a light bulb turning on."

It was Rob and his wife Lorraine's idea to have Daniel live with them while he attended college in Edmonton. He lived in the basement suite of their home. He often shared meals with them, and he carpooled with his brother to the University in the mornings where he then caught the LRT downtown to school.

Rob and Lorraine wanted Daniel to have as much freedom they could give him. This was a challenge, however, because Daniel wanted to do everything. Sometimes, Daniel's wishes, like buying and driving a car, made Rob nervous, even though he admired his brother's enthusiastic approach to life.

Rob and Lorraine hope that Daniel can live as independently as possible, doing something he finds interesting. "Knowing what I do of him and his capabilities," Rob grins, "I think that can be something quite sophisticated."

Donna and Ray Desjardins

Having a child with Down Syndrome was a shock for Donna and Ray, but not for long. A turning point for Donna and Ray came when a parent from the Gateway Association visited them in the hospital. She was the mother of a child with Down's, and she showed them a picture of

her 16-year-old daughter riding a bike. "Our son's going to be able to ride a bike!" Donna said to her husband. From that moment on, and from that very modest goal, Donna and Ray have been active in making sure that Daniel has every support he needs to be able to live a full and rewarding life.

But a number of battles lay ahead. On Daniel's first day of kindergarten, the Desjardins received a phone call from the school telling them that Daniel's behavior was unacceptable. Along with a number of other parents, they banded together and went to Social Services to request help. The road ahead was difficult, but the Desjardins fought hard to give Daniel the right to be educated in a fully integrated setting.

"Daniel was the icebreaker through all of his years in the educational system," Donna explains. "He was the first child with a developmental disability to be included in every class. He had to show the teachers what he could do." When Daniel graduated from high school, the entire community of St. Paul was on hand to celebrate. "And when he threw his hat in the air," Ray grinned, "there was not a dry eye in the place."

"Daniel is a lesson in this busy world that we live in," Donna says. "He reminds us of the 'realness' of life, the love and the caring, and all those things that are truly important." "Patience has never been one of my virtues," Ray admits, "but Daniel has helped me realize just how much he can achieve if we give him the time to properly evaluate and react to life's many challenges."

Part 2. About Person-Centered Planning

Person-Centered Planning is a process used to create a plan, which includes a personal vision and the means to achieve that vision. Sometimes it is a formal process involving a trained facilitator. Sometimes it's informal – like when a few family members sit around a table and just talk about the future of their family member with a developmental disability.

Person-Centered Planning involves the individual with a developmental disability, along with their family members, friends, and other important people in their life. Through a series of discussions, they help the individual develop a personal plan. This plan looks to the future, usually covering a span of three to five years, although it can be longer.

Person-Centered Planning isn't new. It's been used for more than 20 years as a way of meeting the needs of individuals with developmental disabilities and their families.

Person-Centered Planning is not a fad or something new and untried. It began in the 1980s, and has been used for more than 20 years as a way of meeting the needs of individuals with developmental disabilities and their families. Person-Centered Planning introduced a much different way of planning services and supports for people with developmental disabilities.

Before then, planning involved fitting individuals to whatever services were available – it didn't really matter what the individual wanted. In those days, individuals with developmental disabilities didn't have much say in matters that affected them, nor did their families. But Person-Centered Planning changed all that by introducing a new way of planning services and supports.

Like its name suggests, in Person-Centered Planning, the focus is on the individual. Services and supports are tailored to what your son or daughter needs in order to achieve his or her personal goals.



Person-Centered Planning involves:

- Focusing the plan on the individual and their family – The plan is designed expressly for your son or daughter.
- Developing a personalized and unique vision, along with plans and support to achieve that vision – The plan belongs to your son or daughter. It can be used for various purposes, such as telling others more about their special qualities or explaining what they need.
- Providing supports as required – Person-Centered Planning looks at what is needed to achieve the vision. It looks first at community-based, natural supports. Then it looks to other forms of services and supports.
- Adapting the plan as well as the services and supports as the person changes –Your son's or your daughter's interests may change. New goals may be set, or some goals abandoned. People in their support network may change. For example, when new friends come on the scene, they may need to be incorporated into the plan.
- Strengthening community connections and creating opportunities for building relationships and making new friends – The heart of Person-Centered Planning is community inclusion. Your son or daughter can meet new people in meaningful community activities. Having friends is an important part of having good life.



Values and Beliefs

Certain values and beliefs form the foundation of Person-Centered Planning.

- **Inclusive Communities** – Your son or daughter should be supported to live a fully inclusive life in the community. Inclusive communities benefit everyone.
- **Full citizenship** – Each individual has unique goals and aspirations. Your son or daughter has the same rights as others in the community to live the life they want.
- **Positive Focus** – Each individual has unique strengths, gifts and contributions. Person-Centered Planning recognizes and builds on those assets.
- **Relationships** – Families and friends are at the heart of a good life for individuals with developmental disabilities. These important people are invaluable in developing and carrying out the plan.
- **Services and Supports** – Person-Centered Planning is not only about services and supports. These are considered at the end of the planning process, not at the beginning. What your son or daughter wants drives the process. Services and supports are only considered when needed.



Questions to Consider

1. Do you know of any families who can share their experience with Person-Centered Planning or about planning in general? If so, who are they? (If you do not know other families, then AACL or the Northeast Alberta Community Board for Persons with Developmental Disabilities can put you in touch with other families.)
2. What are your beliefs about inclusive communities, full citizenship, positive focus, relationships, and services and supports? Do you subscribe fully to these beliefs and values that underlie Person-Centered Planning? Are there any areas where you feel uncomfortable or unsure?



The Importance of Planning

When you have a plan, you are more likely to get to where you want to go. Sounds simple, doesn't it? But the truth is, lots of people never think about planning – at least where their life is concerned. They live their lives, taking what comes their way, rarely thinking about where they would like to be, or what they would like to be doing, next week, next year, in two years time, . . . or five years . . . or ten years. Does this sound like you or your family?

The life your son or daughter wants should direct the supports and services they receive. This is the essence of Person-Centered Planning.

When someone in your family has a developmental disability, planning is even more important. To live a full life in the community, your family member may require services and supports. But without proper planning, the services and supports they receive may control the kind of life they have. But it should be the other way around – the life your family member wants should direct the supports and services they receive. This is called the person-centered approach – your family member is at the center, and the services and supports they receive revolve around them.



Person-Centered Planning – A Way to a More Inclusive Life

Through the discussions in the planning process, your son or daughter can become a more active, involved member of the community. Person-Centered Planning is a way of

- developing a shared vision – your son or daughter along with the important people in their life are all involved in making the plan and creating the desired future.
- listening and responding – people listen carefully to what your son or daughter wants in their life, and they act accordingly.
- supporting positive change – getting a job or a better job, learning new skills, becoming happier and healthier, getting a better education – these are the kinds of goals identified in Person-Centered Planning.
- working together – creating the vision, making the plan, and carrying out the plan all involve people working together – Person-Centered Planning helps develop a stronger community.



Person-Centered Planning – What it is and What it's Not

Person-Centered Planning is

- different for different people – no two plans are alike.
- an invitation to personal commitment – all those involved in the planning process commit to actions that will help the vision become a reality.
- a way of sustaining and enhancing relationships – relationships are key to a good and secure life.
- a tool for building a better life.

Person-Centered Planning is NOT

- a “cure all.” Person-Centered Planning is not an answer in and of itself. It is “taking action” that really makes the difference.
- just another assessment by professionals. Although Person-Centered Planning may be led by a facilitator, its success is based on the contributions and commitment of everyone involved in the process.
- a standard package or routine format. You can't buy Person-Centered Planning “off the shelf.” Rather, it is an individualized process that is different for everyone.



Limitations of Person-Centered Planning

In spite of its advantages, there are some limitations of Person-Centered Planning. Here are a few things people say.

- The best things in life can't be planned. Falling in love, sharing an exciting moment with a good friend, or just enjoying a sunset cannot be planned. (On the other hand, they may be more likely to happen if there is a plan in place that supports the chance of making these things happen.)
- A plan is not a guarantee for a good life. (True, there are no simple solutions to the complex problems of life. But, generally speaking, a plan is better than no plan at all.)
- Formal planning is not always the right thing to do. In some circumstances, there are more important things to do for someone. Planning can be a low priority, depending on what is happening in a person's life. (But, it is a good idea to plan at least informally.)

With planning, including Person-Centered Planning, great changes are possible. Consider the story "Meet Mark Tremblay – A Great Storyteller," which describes how a young man moved from living in an institution to being an involved participant in his community. In making transitions like the one illustrated in this story successful, planning is essential.



Meet Mark Tremblay – A Great Story Teller

Mark Tremblay was born in Lac la Biche in 1958. When he was 7 years old, he left his family home to live at the Michener Centre, an institution for people with developmental disabilities, located in central Alberta. "I was sent there because I had a bad temper," he explains. "I have some kind of a brain disorder and the medication I was on was making me bananas."

"It was terrible there," Mark recalls. "Some of it wasn't bad. But how would you like to pick 200 acres of potatoes? I had to pick the potatoes out of the fields. They'd be put in storage rooms. Then we'd pick the carrots and turnips. I worked in the farm, too. I milked cows. Lots of them. Man, there was more than you could ever think of!"

Mark was 21 when he finally left Michener Centre. "It took my family a long time to get me out," he remembers, "about a year and a half. You have to go through all these procedures. They send you to a couple of places to see how you're doing. If you do OK, then you get out."

Because his family had moved to St. Paul, Mark decided to make the town his home too. He spent two years living in a group home before moving into his own apartment in what he calls "the 40-suiters" downtown. He's been living there ever since.

Mark is a born storyteller. He loves to talk, and he is very outspoken. He also has a flare for exaggeration and a dry sense of humour. Over the years, he's had a variety of work experience. One of his first jobs was janitorial work. "I got that through my support worker," he says. "We cleaned campsites at lakes, cleaned firepits, picked up fishguts and junk. Sometimes you got a nice gut on your shoe and you didn't smell so good!"

Other jobs also spring to his mind. "I used to help make truck boxes for farmers. I used to weld stuff. I wasn't much good at it, but I did what I had to do. We had a funny guy there, he used to weld his pants to the table."

Mark laughs for a moment and then races on. "Lately, I've been working too much. I was doing janitor work in two different places at the bingo hall nights and afternoons, and at the recycling depot mornings. I was cleaning steel granary bins, too. It was too much. I didn't have time to sleep."

Because Mark likes to do lots of things when he has time, he's recently cut back on his work. "I like to walk," he says. "I clean up my apartment, and I like to do paint-by-numbers and jigsaw puzzles."

But what Mark likes most is make people laugh. "I make people laugh lots," he says proudly, "by just saying real funny things. I make them laugh real hard. I'm good at that. I make jokes. I do a lot of funny things."

With the help of his family and his support workers, Mark lives an independent life. "My aide does a lot of things for me. He takes me out shopping. He does whatever I think I need. He makes sure I don't go overboard when I get my AISH cheque."

"And I have a good family," he continues. "My brother-in-law is a farmer. He brings his toolbox over if I need help. My brother helps out, too. And my Dad's always around if I need help. And whenever something big comes along, my mom and sister are the experts."

Mark has come a long way from his early days in the institution. Anger is a problem for him at times, but he has learned ways to keep it under control. "I have to stay away from stress and from people that drive me bananas," he says. "Then it's not so bad."

Clearly, Mark has many skills to offer. He enjoys being with people, and he's eager and willing to try new things. Listening to him speak, one gets the sense that Mark has the gift of turning every event in his life, happy or sad, into a good story.

And he's a great storyteller.

Part 3. How Person-Centered Planning is Done

What makes Person-Centered Planning so unique is that many people are involved in the development and implementation of the plan. With your son or daughter at the center of the process, people gather around, offering support and encouragement, and helping to create a personal vision and plan to realize that vision.

Usually the process starts by having a meeting. It may be a formal meeting lead by a facilitator. Or it may be informal – just a gathering of the family and others involved with your son or daughter, or even a few people sitting around over a cup of coffee.

(Hint: Even if the meeting is informal, it's a good idea to have someone write things down.)

Steps in Person-Centered Planning

Basically, there are three steps in developing a Person-Centered Plan.

Stage 1. Creating a vision – The “what” of the plan

Stage 2. Making a plan – The “how” of the plan

Stage 3. Implementation – The “doing” of the plan

Steps in
Developing a
Person-Centered
Plan:

1. Creating a vision
2. Making a plan
3. Implementing the plan



Here are the types of questions that are addressed at each phase.

1. Creating a vision – This phase of Person-Centered Planning looks at hopes and dreams. It involves discussing questions, such as the following: What does your son or daughter want in life? What kind of home do they want? What kind of work does your son or daughter want to be able to do? What kind of life do they envision in their community?
2. Planning – In this phase, the planning process looks at how the hopes and dreams can be achieved (or at least worked toward). Questions, such as the following, are discussed: To attain the vision, what goals need to be met? What steps are required to achieve these goals? Who can help your son or daughter attain these goals?
3. Implementing the plan – In this phase, the plan begins to be put into place. Actions are taken so that your son or daughter begins to make progress toward achieving some of the hopes and dreams identified earlier. In this phase, questions such as the following are addressed: Is the plan actually working? Is your son or daughter making progress by attaining goals and working toward the vision? Are any changes required? In this phase, it is not unusual for goals to be replaced by other goals as new interests develop.



Using a Facilitator

Families and individuals can do their own planning, but some prefer to use a facilitator or planner. If you decide to use a facilitator,

- Know the values of the facilitator – The facilitator's values will be more powerful than any planning tool or process. So make sure the facilitator believes in the same things as you do, especially beliefs about inclusion, interdependence, and so forth. Get to know the facilitator first before engaging in the planning process.
- Know the skills and abilities of the facilitator – Not all facilitators are equal. For example, some are more creative, others are more capable of working with individuals who have communication challenges, and still others are better able to solve problems or resolve conflict. Ask for recommendations from families who have been involved in Person-Centered Planning.

Organizations like the Alberta Association for Community Living (AACL) or the Northeast Alberta AACL Family Voices Network can provide names of families as well as contact information for specially trained planners. Also, your local PDD service coordinator can be of assistance in locating a facilitator. Contact information is provided at the end of this Guide.

Questions to Consider

1. Does your family intend to do the planning with the assistance of a facilitator? If so, do you have someone in mind? If not, which friend or family member will help guide the process? Who will take notes?
2. If you do not have a facilitator (and want one), how might you find an appropriate person? Who can you contact for recommendations?

Social Support Networks are a part of everyone's life. They do not have to be organized formally to provide support.

Who is Involved in Person-Centered Planning?

Individuals with developmental disabilities need people in their lives who hold a positive view of them and their future. Your son or daughter needs people who are actively involved in their life. In these freely given, personal relationships, there is a commitment to act – to do things that will help bring about the vision that forms the basis of the plan.

Creating a vision and developing and implementing the plan should include those people who know your son or daughter best and are who are able to contribute to the process. In some families, there may be six to eight people or even more; in other families, only one or two other people are involved.

The terms "Social Support Network," "Natural Support Network," or "Circle of Support" are sometimes used to describe the people who gather around individuals with developmental disabilities in order to offer support and help to attain their vision. These people can be involved in developing the plan; they offer to do certain things that help the vision become a reality.

Your son's or daughter's Social Support Network consists of the people involved in making their vision become a reality. Cultivating people to be part of that network is important for your son or daughter to live an inclusive life in the community.

The people in your son's or daughter's social network will likely change over time. Some people may leave and others will join. For example, if your son or daughter gets a new job, their new employer or a co-worker may join the group. Or if someone moves or becomes too busy to play an active role in your son's or daughter's life, they may leave the group or step back for a while.





The process of developing a social support network, ideally, begins in childhood and continues throughout life. Indeed, some adults with developmental disabilities have friends they met in school and who continue to play an important part in their life. Co-workers, team members, and neighbours may be part of your son's or daughter's social support network, as may their school teachers, support workers, or sports coach, to name a few. Cultivating people to be part of the social support network is important for your son or daughter to live an inclusive life in the community.

Other Considerations

- Be aware of the values people bring to the planning process. For example, do the participants support community inclusion?
- Are there any conflicts of interest? For example, is anyone in the group going to benefit financially from the decisions that may be made?
- Make sure families are involved appropriately – Family members typically know the individual best and certainly know them longest. Their needs and wishes need to be respected.



Questions to Consider

1. Who are the people in your son's or daughter's social support network?

Hint: Some people find that drawing a diagram helps to clarify who might be part of this network. Draw concentric circles with your son or daughter at the center. Then write the names of people inside the circles reflecting the closeness of their relationship to your son or daughter.

Some families find it helpful to consider all the people that their son or daughter encounters over the week. That way they won't overlook someone who might be an excellent member of the support network (e.g., teacher, church leader).

2. Which of the people you identified above would be most appropriate to involve in the Person-Centered Planning process?



The story, "Meet the Diatel Family," illustrates the importance of family involvement and the creative solutions that parents can find. Part of their solution involved building a new home, with a suite where their son and his roommate could live.

Meet the Diatel Family

Part of their vision involved building a new home.

The challenges of having quadriplegia and living with cerebral palsy haven't prevented 22-year-old Aaron Diatel from having his own home. Using a Person-Centered Planning process, his parents helped to devise a plan where they could be part of their son's life without having to be with him 24/7.

When Aaron became an adult, his parents had to make a hard choice: to have Aaron live in a group home or to continue having him live at home, where the family was lacking privacy (because of workers) and Aaron was lacking the opportunity to grow.

They wanted Aaron to receive the best care possible, and, through a planning process involving several people involved with Aaron, they arrived at an innovative idea that worked best for everyone. Aaron needed a home at home. So the family decided to create a mother-in-law suite where everyone could have their own space. "We had come to a crossroads," his father explains, "A group home or stay where we were. We chose this. In the long run it was the right thing to do."

Today Aaron is living with a roommate, another young man in a wheelchair. The two-bedroom suite includes an office, kitchen, bathroom, and living area. To make the space wheelchair friendly, it is equipped with wheelchair ramps, a handicap shower and a lift system above the beds. All of the doorways and hallways were also widened to accommodate the wheelchairs. They have a six-person staff (rotating shifts) who attend to them during the week. On the weekend, Aaron is looked after by his family when his roommate goes home.

"Aaron's grown leaps and bounds, they both have," his mother says. "He's embraced his independence. And if he's having a bad day or just wants to visit, he comes over." She adds, "A bit of privacy allowed us to take time out, to get a break during the week."

Some of the changes his family and workers have seen in Aaron include more willingness to embrace friends of his own. "He's beginning to stand up for himself and his non-verbal communication skills have improved," his father explains. "Living with us wasn't giving him the opportunity to socialize, now he has peer camaraderie."

Part 4. Creating a Vision

As noted earlier, Person-Centered Planning involves three phases:

1. Creating a vision – The “what”
2. Making a plan – The “how”
3. Implementing the plan – The “doing”

In each of these phases, meetings are held with the individual and the family as well as with others who gather around to offer their ideas, support, and commitment. When Person-Centered Planning is done formally with a facilitator, usually two or three meetings are involved.

In the Implementation stage, meetings are held on a continuous basis. Frequency depends in the detail involved in the plan. Some families hold meetings only once or twice a year, others meet monthly to see if things are going smoothly.

Questions to Consider

1. What meeting schedule would be most appropriate for your family? A few formal meetings a year with a trained facilitator? Monthly meetings with a group of supportive family members and friends? Frequent informal discussions? Some other option?
2. Where and when might these meetings take place?



The Person-Centered Planning process starts by creating a vision of the future your son or daughter wishes to have.

There are many creative ways that families can capture the vision and plan. Photographs and even video can be used to show the future your son or daughter envisions and the plans to get there.

Step 1. Creating a Vision

The Person-Centered Planning process starts here. A meeting is held with the individual and group of people who know the individual well. Together, they create a vision of the future the individual wishes to have.

The hopes and dreams and other aspects of the vision can be recorded in various ways. Some families recommend using a flipchart or large sheet of paper to gather everybody's thoughts and ideas. These can later be transferred into a scrapbook so that all the information is easily available for use at a later time.

Some families have used innovative ways of capturing the vision and plan. For example, one family created a video that their daughter could show to the people involved in her life. The video explained what her interests were, her hopes and dreams, and the plans that had been made to help her achieve her vision. The family found that this was an especially effective way of letting their daughter's support workers know who she was, especially when there was turnover.

One young man used photographs and pictures to illustrate what he wanted in life. He pasted these into a scrapbook and, with his sister's help, wrote a caption under each, explaining what the picture conveyed about the life he wished to have.

Questions to Consider

1. What is the best way for you to document your son's or daughter's plan?
2. How might you communicate the plan to other people involved in your son's or daughter's life?

Looking at Strengths

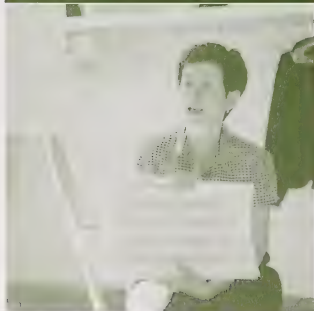
Start by talking about your son's or daughter's strengths and assets that will assist in planning and obtaining the future they wish to have. Questions such as the following will help obtain this information:

- What are your good qualities? What makes you unique?
- What are your talents, assets, and abilities?
- What do you have going for yourself in your life?

Jot down the answers to these questions. Diagrams or graphics may be used to help record this information.

Questions to Consider

1. What are your son's or daughter's unique qualities?
2. What kinds of talents, assets, and abilities does your son or daughter possess?



Looking at the Past and at the Present

In this part of the Person-Centered Planning process, have a discussion of what has gone on before, in the past. Encourage your son or daughter to tell their "story," and ask questions such as "What important events have occurred in your life?"

The answers to these questions may be placed on a large sheet of paper, using diagrams and short descriptions to show the flow of events and important themes.

Next, consider what is currently going on now in your son's or daughter's life. Answers to questions, such as the ones provided below, help to get the information needed to fill out this part of the process:

- Where are you living? Do you have a roommate(s)?
- What do you do in a typical day?
- Where are you employed? Do you do volunteer work?
- Are you going to school? If so, what are you studying?
- Who are your friends? Who helps you if there are difficulties?

Again, a diagram and short descriptions can be used to help to capture this information about the present status of your son's or daughter's life.

Questions to Consider

1. What important events have occurred in your son's or daughter's life?
2. What are the main features of your son's or daughter's life today?

Likes and Dislikes

To get an idea of what your son or daughter wants (and doesn't want) in life, ask questions such as

- What are your interests?
- What kinds of things do you like to do?

Also, to get a complete picture, ask negative questions, such as:

- What don't you like to do?
- What are your fears? What things cause you to worry?
- What is the worst thing that could happen to you?

Questions to Consider

1. What are your son's or daughter's interests? What does he or she like to do?
2. What doesn't your son or daughter like to do? What are his or her dislikes?
3. What does your son or daughter fear?



When considering your son's or daughter's future, don't be afraid to dream. There are many possibilities.

Looking at the Future

Next, explore what your son's or daughter's life might be like in the future. Again, use a diagram and short descriptions to write down this information. Consider questions such as the following:

- Where would you like to live? With whom?
- What kind of career would you like?
- What kinds of things would you like to do in your spare time?
- What are your dreams and goals?

The dreams that your son or daughter has for the future can be many and varied. Too often, individuals with developmental disabilities and their families have learned not to dream, to compromise and to settle for less. But the planning process is a place to break free of the misconceptions and conventions that can harness your son's or daughter's future.

Don't be afraid to suggest things that might be overlooked. Be creative and innovative. For example, one young man has a trip to Mexico as part of his vision. Another is taking guitar lessons as a way to achieve his goal of being a country and western singer. An older woman, in her plan, decided to retire. Another is taking art classes and learning to paint watercolours. Starting a business, going to college or university, buying a house – all these things are possible, so don't sell your son or daughter short by being afraid to dream.



Questions to Consider

1. What are the main features of the life your son or daughter envisions?
2. Are creative or innovative things included in the life your son or daughter envisions? If so, what are they?



Gordon Drave's story provides an excellent example of someone who was not afraid to dream. After living in an institution for more than 20 years, Gordon returned to his community and became a woodworker. Today, he operates his own woodworking business and is an active member of the community.

Meet Gordon Draves – A Local Entrepreneur

Gordon Draves is a man with a vision. He has learned to take action and be outspoken – a far cry from his early years.

Gordon recalls when, as a child, he overheard doctors telling his parents that he was "too blind and deaf, and that people thought he was crazy." Gordon hated living in Michener Centre – the lack of privacy and locks everywhere. "Locks to keep people in, not to keep them out!" he recalls.

In 1980 Gordon was liberated from the confines of the institution and moved to St. Paul into a residence at the St. Paul Abilities Network, where for the next 7 years he learned all the skills he would need to live independently. Gordon fondly remembers the day he moved. "My life changed quite a bit, I felt free."

His time at Michener left him starving for social interaction. In response, he joined in many sports, including floor hockey, slow-pitch, speed skating, and Junior B hockey and even served as assistant hockey trainer for several years. With the help of Special Olympics and SPAN, Gordon has been to Parsons City, Kansas three times, Vancouver for softball in 1990, and all across the western provinces for sports events.

In 1987, Gordon moved into his own apartment. Then, in 1998, he and two close friends moved into a three bedroom two-story house of their own, just ten blocks from work. Gordon likes the fact that, "I can be my own boss in my house" and although he admits there can be problems living with roommates he also enjoys having someone around to talk to and share chores. Gordon says that, "Even when we don't get along it's still better than living in an apartment."

With his arrival in St. Paul through Habitat Enterprises, a vocational training centre, Gordon learned woodworking and other skills. For 3 1/2 years, he worked with farmers doing farm work, including seeding and harvesting. Then, he returned to his workshop.

When budget cuts forced the woodshop to close, Gordon moved on to become an integral part of the steel grain bins assembly team. However, Gordon never gave up on his lifelong love – the woodshop.

Then in 2001, he negotiated to go out on his own to start his own specialty woodwork shop. The agency provided Gordon with the basic tools, and a separate shop and some support to get started, and Gordon R. Draves Woodworking was established.

Today Gordon spends much of his working day and many of his after-work hours in his little shop where he builds various types of flower planters, potato and onion bins, pet dish containers and many decorative shelving plans.

His success is already apparent. In the few short months he has been working, Gordon has managed to assemble an impressive selection of tools (most purchased out of his business profits). He is eagerly learning the administrative and financial management aspect of his business, and he is already a tireless promoter of his service.

Gordon does not expect to get rich – only happy with his home, with his business, with his life. Gordon faces each day with his shoulders back and a smile on his face. He has taken control of his destiny and is plotting the course of his future.

The sky is the limit Gordon, reach for the stars!

This story was written by Gordon Draves and Verna Ostopovich (Outreach Supervisor, SPAN)

Areas of life planning include:

Relationships

Personal Growth

Community Inclusion

Employment

Health and Well-Being

Having a Home

Part 5. Areas of Life Planning

The vision that your son or daughter, along with you and others in the family, creates may address a number of areas. These life planning areas are described below.

Relationships

One of the most important life areas for individuals with developmental disabilities is the nature of the relationships in their life. Family and friends are important for helping to create a sense of belonging and value. They also provide access to a range of natural supports. These relationships can help your son or daughter to attain their personal vision.

When planning with your son or daughter, consider questions, such as those provided below, to explore the nature of their relationships.

- How many relationships does your son or daughter have?
- What kind and variety of relationships do they have (e.g., friends, intimate relationship, acquaintances, professional, family)?
- What is the quality of their relationships (e.g., lifelong, sustained over distances)? Are any of these relationships reciprocal? If so, how is this demonstrated?
- How much time does your son or daughter spend with friends and in other forms of relationships?
- What community activities does your son or daughter engage in with friends and others? Are these activities of mutual interest?
- Does your son or daughter enjoy their relationships? Are the relationships valued by all parties?
- Are there adequate supports to facilitate the development of relationships? To sustain relationships?

Questions to Consider

You may wish to use the questions in this section to add detail to the vision of your son's or daughter's life.

1. What are the most important relationships in your son's or daughter's life?
2. Is your son or daughter satisfied with the current relationships in their life? Are there any areas where changes may be required?
3. Do the supports that your son or daughter receives facilitate the development of relationships? If so, how? If not, what might be done to make it easier for your son or daughter to build relationships?



Personal Growth and Empowerment

This life area considers how your son or daughter has grown, for example, in the responsibilities they have assumed, decision-making capacities and opportunities, decisions they have made, and their personal responsibility for those decisions. Personal growth may be evidenced by increased self-confidence and autonomy.

Note: In most instances the opportunity to be supported in making decisions and exercising choice should be reflected in all of the life areas of life.

Dimensions of personal growth and empowerment include the following:

- How does your son or daughter demonstrate self-confidence?
- Is your son or daughter comfortable taking new (reasonable) risks that promote growth and opportunity (e.g., trying a new community activity, assuming a new job, trying new foods)?
- What are the different ways your son or daughter expresses growth? (e.g., art, activities, challenges, choices, decision-making, responsibility for decisions, assuming new responsibilities)
- What opportunities have been created and supported to enable personal growth and empowerment?
- How has your son or daughter changed over time in their capacity to make decisions and the type of decisions (e.g., differences in nature of decisions, capacity to speak for themselves, capacity to represent the interests of others)?
- Has your son or daughter had the opportunity and support to pursue inclusive lifelong learning both formally and informally (e.g., inclusive post-secondary education, night courses, online courses, workshops, tutoring)?
- Has your son or daughter had the opportunity for travel?



Questions to Consider

1. Is your son or daughter a self-confident person? Is he or she comfortable taking on new things?
2. What does your son or daughter do that reflects their personal growth?
3. How do you consider your son's or daughter's decision making ability? Has this ability changed over time?
4. What kinds of opportunities has your son or daughter had for personal growth?



Community Inclusion

Relationships, personal growth and all the other dimensions of a good life are more likely to happen when your son or daughter is embedded in community life. This area of life requires more than presence in the community – it requires membership and participation in both formal and informal activities. It is in this life area that the gifts and contributions of your son or daughter can be recognized and harnessed. Your son or daughter should be a valued, participating, and recognized community member, not simply physically present.

Dimensions of this life area include the following:

- To what community groups and organizations (formal and informal) does your son or daughter belong?
- How has the community recognized and accepted your son or daughter as a person with unique gifts and talents?
- Has your son or daughter been invited to participate and/or join a group or organization? How welcome have they been? What activities and roles has your son or daughter assumed or been invited to assume?
- Describe the contributions your son or daughter has made to the community and any reciprocal contributions. How have both your son or daughter and the community been enriched by the experience?
- Illustrate how your son or daughter has achieved a sense of belonging within the community? Are they missed if they are not present?
- Does your son or daughter have volunteer roles in the community? How are these roles recognized and valued?
- Does your son or daughter have the opportunity to engage in a range of cultural and leisure activities and pursuits?

Questions to Consider

1. To what extent is your son or daughter included in your community? Does your son or daughter have a sense of belonging to the community?
2. How does your son or daughter contribute to the community? How does the community contribute in return?
3. What kinds of opportunities does your son or daughter have to engage in cultural and leisure activities and pursuits?
4. What kinds of changes, if any, are required to help your son or daughter achieve their vision with regard to community inclusion?

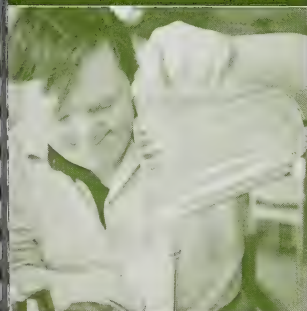


Health and Well-Being

This life area includes, but is not limited to, the fundamental elements of safety, personal security, and physical health. It also includes the need for individuals with developmental disabilities to have a place to live and the opportunity to enjoy life.

To engage in a discussion with your son or daughter about this area of life, consider questions such as following:

- Does your son or daughter have opportunities to express themselves spiritually? How is this supported? Does your son or daughter participate in an inclusive faith community of their choice?
- How is your son's or daughter's cultural identity recognized, valued, and supported?
- Is your son or daughter in good physical and mental health? How is their physical and mental health being maintained (e.g., nutrition, regular exercise, regular health care, counselling if necessary, emotional support as necessary)?
- In what physical and creative activities does your son or daughter participate? Do they have hobbies or other leisure pursuits? Are these inclusive and engaged in with friends?
- If your son or daughter had to be hospitalized, how would they be supported?
- Does your son or daughter have the opportunity to fulfill their desire for intimate and personal relationships?
- Is your son or daughter supported to have a safe lifestyle, while balancing the need for reasonable risk? How are issues of safety and protection from abuse addressed?
- Does your son or daughter have a positive self-identity and sense of self-worth? Does he or she have a sense of belonging and connectedness to family, friends and community?
- Does your son or daughter have aspirations for a better future? What are these and how might they be realized?



Questions to Consider

1. To what extent does your son or daughter feel a sense of safety and comfort in your community? What kinds of changes, if any, are needed to help your son or daughter have a greater sense of well-being?
2. Does your son or daughter have any physical or mental health concerns? If so, what are they?
3. What kinds of opportunities does your son or daughter have to engage in creative and spiritual activities? Is there a need for more opportunities? If so, how might this be achieved?



Employment

Employment is an important life area as it ensures access to an adequate income. This area also includes the opportunity to continued education, to form a career identity, and to secure meaningful employment.

To engage in a discussion with your son or daughter about this area of their life, consider questions such as the following:

- Does your son or daughter have opportunities for career development and planning? How are their career aspirations being supported and realized? What is their career history? Are there ongoing opportunities to advance and learn?
- Is your son or daughter employed in an inclusive workplace? Do they receive benefits and a competitive wage? What hours are they working? How long have they been working? Would your son or daughter like to work more hours and how might this be realized?
- If your son or daughter is unemployed or underemployed, how is this being addressed? If they are dissatisfied or unfulfilled by their current employment, how is this being addressed?
- If the workplace is unionized, is your son or daughter a member of the union?
- Does your son or daughter have valued roles in the workplace? Is he or she included in workplace staff development and leisure activities?
- If your son or daughter has an entrepreneurial spirit, how is this being realized?
- Does your son or daughter have friends at work? How are these relationships supported? Do these relationships exist outside of the workplace?
- As a result of employment, does your son or daughter have increased purchasing capacity and improved lifestyle?
- Is there a need for financial planning? If so, how is this supported?

Questions to Consider

1. Does your son or daughter have a job? If so, what kind of work is your son or daughter doing? Is the work done in an inclusive setting?
2. Is your son or daughter satisfied with the amount and type of work they are doing? If not, what kinds of things are causing dissatisfaction?
3. What kinds of changes, if any, are needed to help your son or daughter achieve their vision with regard to employment?



Having a Home

Having a home is a universal human need across cultures, time, and ages. Home contributes to a sense of security – a place from which to both step into the world and retreat from it. Home also provides an essential means by which to express one's personal identity. A good home is a source of strength and comfort.

Dimensions of this life area include the following:

- Does your son or daughter own their home? If they are interested in home ownership, how is this being pursued?
- If your son or daughter is sharing a home, are they living with others with whom they wish to share their life? Do they have a choice as to whom they are living with? Do they have the choice to live alone?
- Is your son or daughter able to afford the home they would like to live in? If not, how is this being addressed?
- Does your son or daughter choose the staff who support them in their home?
- What kinds of relationships does your son or daughter have with their neighbours? How are these relationships being supported?
- How does your son's or daughter's home reflect their personal identity and lifestyle choices?
- How does your son or daughter express hospitality? Do they have friends and family visiting (e.g., inviting friends or family over for dinner, hosting events)?
- How does your son's or daughter's home life and routine reflect their personal identity and choices (e.g., private space, opportunity to relax)?
- Is your son's or daughter's home a place where they feel accepted for who they are? Does their home provide a sense of comfort, safety and security?
- If your son or daughter does not live in a place that is truly their own home, how is this being addressed? If they are not happy with whom they are sharing their home, how is this being addressed?
- Is the home well looked after and in good condition? How is it maintained or what is being done to improve the quality of the environment?

Questions to Consider

1. How would you characterize your son's or daughter's living arrangements?
2. Does your son or daughter feel that the place where they live is their home? What kinds of things create a sense of comfort and security?
3. What kinds of changes, if any, are needed to help your son or daughter achieve their vision with regard to their home?



The importance of having a home and the role it plays in supporting individuals with developmental disabilities is evident in the story "A House, a Home and a Garden," which tells the story of Duane and Yvonne and the home they created.

A House, A Home, and a Garden

Yvette Corbiere and Duane Bird live in a small two-bedroom house in Vegreville. While the house may be small, the garden is large. This year the couple planted peas, potatoes, carrots, beets, tomatoes, lettuce, onions, dill, and cucumbers. Everything is thriving. Up against the fence, red raspberries droop heavily from their vines in the sun, and soon the fruit on the apple and plum trees will be ready to eat. Yvette and Duane are proud of their house and garden, and they should be. In the fall of 2002, it will be their own.

The couple has been together since 1993. Over the years, they have lived in an apartment, a trailer, and a house. But they became tired of renting. "Four years ago," Duane says, seated comfortably in his living room, "I walked into the ReMax office and asked if they had any rent-to-own houses. They had two that we could afford. We decided to buy this one."

Renting-to-own has worked well for the couple. When they combine their AISH cheques, they can easily meet their monthly payments and still have money left over to pay utilities and buy food.

The house has a welcoming feel to it. A full pot of coffee sits ready on the kitchen counter. The dog, Samantha, wags a greeting with her tail. A finch chirps in its cage in the corner of the living room. Two tiny frogs swim in their fish bowl and, in another room, dozens of fish swim happily in two large fish tanks.

Both Yvette and Duane have added personal touches to the house. The couch and loveseat are covered with colourful afghans that Yvette knitted herself. Three large jigsaw puzzles, another one of Yvette's hobbies, hang in the living room and kitchen. "That one there has 3,000 pieces and took me two months to finish," Yvette says proudly, pointing to a wall where the puzzle hangs.

"And here," Yvette says as she walks to the small room beside the kitchen. "Here's what Duane does." Two shelves beside the computer are covered with model airplanes and cars. Duane smiles as he shows them off. "This one's my favourite," he says, holding up a replica of the Starship Enterprise. "I love Star Trek."

Duane is 43 years old. He's an easy-going and gentle man who loves to tell stories and who loves to laugh. Over the years he's had many jobs. But a series of health problems has left him unable to work. Today he keeps busy with the house, and he volunteers for Citizens on Patrol (COP), a community group that helps the RCMP. When he's on call, Duane and a partner drive around the community from 11:00 pm until 3:00 am, making sure that no crime is taking place.

Yvette is 33 years old. She is not as outgoing as Duane, but she clearly enjoys his stories and jokes. She keeps busy with housework, yardwork, sewing, knitting, doing jigsaw puzzles, and taking their dog for walks.

Next year, when the house is paid off, the couple plans to marry. "Our anniversary is Valentine's day," Duane says. "I got down on my knees in front of everybody when I asked her. I gave her a ring. She was so surprised."

Yvette's eyes widen as she remembers the event. "I was surprised," she says. "He gave me two rings." She holds her hand out to show them off. "He always thinks we'll marry," she teases, looking across the room at Duane, "but we'll see."

"When the house is paid off," Duane repeats, "next year. Then we can start to renovate. We want to add on to the house and knock out a wall to make the living room bigger."

Together, Yvette and Duane are able to live without the help of support workers. Home ownership gives them the security of knowing they can stay where they are for as long as they like. It allows them to have as many pets as they want, and to decorate their surroundings according to their taste. It also gives them as much privacy as they want.

"The next time you're in town drop in," they say when our visit is over. Just then, a car pulls up out front. One of their friends has come to visit. Yvette walks to the back door to let him in. Fortunately, there is still coffee left to share in the pot.

Sadly, Yvette passed away on May 19, 2002, at the age of 33. She is missed and we cherish our memories of her.

Part 6. Making Plans and Taking Action

Making Plans

Once the vision is created, the next step is to determine how to get there. This step too is typically done with one or more meetings. The group that meets will likely include the same people who were involved in creating a vision, but it may also include others from the community who can help the individual attain the vision.

These meetings can be formal or informal. In some families, planning meetings are held spontaneously. Others schedule them. Some families like to involve many people from outside the family. Other families are comfortable with doing the planning themselves. Planning should occur in the way that suits your family best.

During this meeting, an action plan will be developed. This will consist of the goals that will lead to the vision. The actions that will help reach these goals and who will be responsible for doing these actions.

To live an inclusive life in the community, it is important to use community resources and natural supports as much as possible. Only when there is a gap between what is available and what is required should paid-for, professional services be considered.

Once the vision is created, the next step is to begin to make plans that will lead there.

Questions to Consider

1. What kinds of actions are required in order to help your son or daughter achieve their vision?
2. How can the resources of family, friends, and natural community supports be used to help your son or daughter achieve their vision?
3. What kind of support or services might help your son or daughter achieve their vision?

How can people participate in the planning?

- Listen to the individual and their family
- Contribute ideas and suggestions
- Volunteer to undertake certain tasks (and follow through!)
- Maintain a focus on the individual



Features of a Good Plan

- Individually tailored
- Addresses the most important areas of a person's life
- A shared vision of community inclusion
- Considers the community's capacity for inclusion and participation
- Commitment to implementation
- Involves community membership, participation, home, friends
- Accepted by the individual and those closest to them
- Provides a foundation for future action
- Accurately reflects what was agreed to
- Specific, clear and accessible
- Includes the capacity for change

The Sample Plans, which are located in the next section of this Guide, illustrate these features.

Taking Action

The plan developed in the previous stage identified goals that would lead toward attaining the vision, as well as actions that would at least start the way toward reaching these goals. It addressed the question "Who will do what and when?"

Plans should include who will do what and when.

Now it is time to look at things like:

- Are there enough existing people and resources to accomplish the goals?
- What additional people and resources are necessary?
- What is working well? What isn't working as well?





Monitoring the plan and its implementation looks at questions such as:

- What does your family member's life look like? Are the goals, or steps toward the goals, being accomplished?
- Are people doing what they said they would do? If not, how can this be corrected?
- What, if anything, needs to change?

Most families find that they need to convene the entire planning group and meet regularly – at least every three to four months and often more frequently. By meeting regularly, the family can ensure that they are on track and their family member is making progress toward meeting their goals and ultimately achieving the vision.

Questions to Consider

1. What kinds of things can your family do to organize and monitor the actions required to achieve your son's or daughter's vision?
2. How, when, and where might meetings be arranged to discuss the implementation of these plans?



The story "Meet the Mackins," illustrates how one family implemented their son's plan and how they ensure that things stay on track.

Meet the Mackin's

Rollerblading and snowboarding became possible for Phillip, as a result of the planning he did with his family.

Phillip Mackin lives an average life for a 22-year-old. He has a full-time job, performs in a band, plays on a bowling league, and has aspirations of going to university and expanding on his dream of owning a business.

Two years ago his outlook wasn't so optimistic. Planning made all the difference. Part of that plan involved a family move.

In the last year, Phillip's life and that of his family have changed considerably. Until recently, the Mackin's lived on a farm where Phillip lived a fairly isolated existence. But since moving to Fort McMurray, that isolation has turned into a full social calendar for Phillip. The Mackins say they can't believe the community events, resources, opportunities, and services available to Phillip and to themselves as well. And they're happy to make use of all that's being offered.

Phillip has a sight impairment as well as severe epilepsy that causes him to have daily seizures. However, with the support of a personal care worker who shadows him, Phillip is now able to lead a mainly independent life.

"He's independent. Jason, his worker, only has to be there if he has a seizure. It's more like guys hanging out, and it works well," Phillip's mother Niki-Lou explains. And Phillip agrees. "You have someone there to support and help you with certain problems, the things you can't do they help you with, but you also teach them," he notes, speaking of the give-and-take of his relationship with Jason. Phillip adds, "I like the independence and enjoy not always having the same people in my life."

The Mackins agree. Now that Phillip doesn't rely so much on his family, they are able to devote more time to other things. And Phillip is pursuing two new interests, rollerblading and snowboarding – things his mother never wanted to do with him.

Phillip's social life has also improved. He is making more friends while attending various events. He has joined a bowling league, and plays guitar in a local rock band. He also works part-time at the Salvation Army.

Phillip likes having the opportunity to teach his fellow workers. He shows them how to do woodworking and sewing, two activities Phillip has mastered so well that he has sold some of his pieces. Phillip hopes to make this a fully operational business in the future, including having employees.

Niki-Lou adds, "It's nice when people approach Phillip that I've never met before. You can't grow and develop under your family's thumb . . . you need independence and a different perspective. When you're with someone 24/7, you don't experience life."

Today, the hardest part for Phillip is figuring out what he wants to do with his life, now that there are so many options open to him. To illustrate – lately, he says, he's been thinking about taking some business courses at the local college and starting a company of his own.

Philip and his parents meet every three months with his support worker, the local Community Service Coordinator, and others involved in his support network to see how things are going and to discuss if any changes need to be made. So far, things have worked out very well, his mother reports, but she adds, "even if there were difficulties, I'm sure we could work things out to Phillip's advantage. The relationships we have with everyone who works to Phillip are fantastic."

Phillip's mother advises, "The basic thing about planning is figuring out what's the dream? What is it that you want for your child? And more important, what does Phillip want? Don't concentrate on the 'how' at first, just keep the focus on the dream. She adds, "Where's there's a will, there's Phillip. He knows he can do these things and lots more. He's realistic, but for him, there's no such thing as failing. You only fail when you don't try."

Sample Plans

The sample Person-Centered Plans contained in this section are composites of the plans of several individuals. Characteristics and other identifying information have been changed to ensure anonymity.

Jackson's Plan

Jackson Smith is a 17-year-old high school student who lives with his mother, Trudy, in Vegreville, Alberta. He is friendly and social, and enjoys meeting people. Jackson is polite and well mannered and gets along with people. He has a good sense of humour. He likes animals and wants to have a pet someday, maybe a collie. Jackson has an extended family in rural Alberta, including one uncle, David, also living in Vegreville. Jackson's father passed away when he was a baby and his mother has never remarried.

To assist with the needs associated with the cerebral palsy that causes him to use a wheelchair and also to accommodate his developmental delays, Jackson currently receives daily after-school supports from a service agency. They also provide respite care two weekends a month. His workers help with bathing and self care, take him swimming twice a month, provide help with homework, and support him in the community.

Jackson enjoys swimming at the local recreation centre and watching sports on television, and looks forward to fishing trips with his uncle. He also enjoys spending summer vacation with his grandmother in southern Alberta.

Jackson is currently in grade 10. He likes school, and plans to graduate. His program includes the usual academic subjects and work experience. He especially likes work experience – his current placement is cleaning equipment at a local sports facility. Jackson's mother is pleased with the school's educational program and with the level of integration and acceptance by other students.

In anticipation of Jackson's 18th birthday and adulthood, a Person-Centered Planning process was conducted. Jackson was invited to share his life dreams and vision of adulthood in the company of his mother, uncle, and school principal. The PDD Service Coordinator was also involved, as was a trained facilitator.





Jackson used words and illustrations to represent his dreams in the areas of home, relationships with others, involvement in the community, and weekday activities. To get an understanding of the significance of these hopes and dreams, Jackson also rated them according to three degrees of importance – I must have ...; It is important to me...; It would be nice if....

Here is a sample of the things that make up Jackson's vision.

"My Home"

- I must live in my own place, perhaps with a roommate.
- I must live in Vegreville.
- I must have a cat or dog.
- It is important for me to have a home that's accessible.
- It would be nice to have less staff around.

"My Relationships"

- I must have my mom in my life.
- It is important for me to keep my friends and make some new ones.
- I would like to have a girlfriend, and maybe get married someday.
- It would be nice if I could maintain my relationships with other family members.

"My Community"

- I must have swimming.
- It is important to me to go to the movies.
- It would be nice to travel to California.
- I would like to work in a sports facility.
- It would be nice if I had a van so I could travel around Alberta and meet people.

"My Day"

- I must have fun.
- It is important for me to get paid for working.
- It would be nice if I had a job.

With the help of the facilitator and others in the group, Jackson was able to create an extensive outline of family members, friends, teachers, support workers, and community members who he encounters in his daily life, trusts, and feels comfortable with.

He then created a list of people who were considered important influences in his life and who he wanted to be part of his support network. Some adjustments were made by Jackson's mother, and the resulting list consisted of the following people:

Jackson's mother, grandmother, and uncle

A family friend

Jackson's key support worker

Jackson's teacher

PDD Service Coordinator

Jackson sent out invitations, asking the above people for their assistance in helping him achieve his vision. An interactive process of action planning then occurred over the course of two separate sessions. Not everyone that Jackson had invited was able to attend both sessions. Collectively, they brainstormed a series of actions they believed would lead to Jackson's attainment of his vision of adulthood. Network members then offered their assistance in conducting or advocating the follow-up of the noted actions. A series of timelines were also established by the group to review the status and progress of the actions.



Here is a sample of some of the goals and the related actions.

Goal: To live in a home that will allow a dog or cat.

- Actions:**
- a) Investigate some rental opportunities in and around Vegreville that will allow pets. (key support worker)
 - b) Discuss what attributes Jackson wants in a pet. (mother)
 - c) Look up information about various pets. (teacher)
 - d) Visit local pet stores, kennels, animal shelters, etc. to experience different types of pets. (teacher)

Goal: To live with less staff.

- Actions:**
- a) Develop independent living skills. (key support worker)
 - b) Investigate other supported living arrangements to minimize staffing presence. (PDD Service Coordinator)

Goal: To work for money that will pay for “fun” things.

- Actions:**
- a) Provide a variety of work experience opportunities so Jackson can determine what he likes to do. (teacher)
 - b) Assist Jackson to develop work skills related to his vocational interests. (teacher, support worker)



Emily's Plan

Emily Croft is a 20-year old woman who has been receiving assistance from PDD for two years. She has a job coach who helps her in her work as a receptionist at a local service agency, and she lives in a group home with two other women. Emily has a few health problems. She has the beginning stages of diabetes and is quite overweight. However, her doctor told her that if she got more exercise and lost weight, she likely would not develop diabetes.

Emily, her older sister, and her parents immigrated to Canada in 1995. (One older brother, John, remains in Germany.) They made their home on a farming acreage north of Lac La Biche. Emily attended high school in town, but says she never really fit in or made many friends because she was so shy. She dropped out of school in grade 10 and helped on the family farm until her 18th birthday. At that time she decided to move into town. With the help of her older sister and the local PDD Service Coordinator, Emily moved into the group home where she continues to live today.

Emily and her sister, Lynn, have a very close relationship. Lynn is married and has a two-year-old son and is expecting a second child. Emily has a loving relationship with her nephew who clearly loves his Auntie Emily. He runs to her and climbs onto her lap to snuggle upon seeing her. Emily responds very naturally, snuggling and cradling him in her arms, and the two are clearly happy when sharing each other's company. Emily says she loves her nephew and welcomes having a second nephew or niece in the next few months.

Emily's first language is German – which her mother proudly states, “she speaks perfectly,” and jokes that when she came to Canada, she “only knew swear words” in English. Emily has made remarkable progress in learning English, and has little trouble expressing herself. Her German accent contributes to her charm. She speaks German at her parent's home and loves listening to traditional German folk music reminiscent of her birthplace. Emily says that she misses her older brother and wishes they had more contact.





Emily does volunteer work at the Seniors Lodge, where she helps with Bingo on Friday nights. A few of the residents speak German, and they especially look forward to visiting with her.

Emily works part-time as a receptionist at the local Mental Health office where she answers the phone and types letters. She has a job coach, Maria, who helps her get to work on time, oversees her work, and gives her prompts as necessary. Emily likes meeting people through her work, but finds typing very difficult. She says that she would like a different job. Her dream is to work with children, perhaps in a daycare centre.

Emily gets together with her sister and parents every few months to talk about her life and how things are going. Sometimes they have more formal meetings with the local Client Service Coordinator present, or invite other people involved in Emily's life. Emily is keeping a scrapbook that is titled "All About Emily," where she writes about her interests and special things about her. She also writes about the dreams she has for her future, and pastes in pictures that reflect the kind of life she would like. Her family often uses the book to discuss what Emily would like to be doing in her day-to-day life, as well as in the future, and if there are any changes required.

Here is a sample of the kinds of plans that they have developed, based on the hopes and dreams written in Emily's scrapbook.

Emily has pasted many pictures of people working with children into her scrapbook and talks about how much she would like to work in a daycare centre someday. She knows of another young woman with a developmental disability who is taking a college program studying Early Childhood Development and thinks this is something she might like to do in order to get a job in this field. She discussed this with her family and they developed the following plan to explore this avenue further:



Goal: To get more education in order to work as a child care worker.

- Actions:**
- a) Explore options about finishing high school. (Community Service Coordinator)
 - b) Write away for information on college program. (Maria, job coach)
 - c) Visit campus program. (parents)
 - d) Visit local day care centres and explore possibility of volunteer work. (Maria, job coach)
 - e) Talk with someone who has taken the program. (parents)

Emily has many photographs of her brother, John, who resides in Germany. She frequently talks about how much she misses him. Although they speak on the telephone once in a while, she would like more contact with him. Also, she exclaims, "I would love to visit him at his home!" She and her family develop the following plan around this area:

Goal: To have more contact with John, her older brother who lives in Germany.

- Actions:**
- a) Learn how to use e-mail so that she can send messages to her brother as often as she would like. (Maria, job coach)
 - b) Investigate cost of making a trip to Germany for a visit. (Lynn, older sister)

Emily talks about being concerned about getting diabetes and says she would like to be less heavy. Her sister agrees that she too would like to lose "a few pounds." Emily and her family develop the following plan around this area:

Goal: To lose weight and improve my health.

- Actions:**
- a) Go for walks after dinner three times a week. (Lynn, older sister)
 - b) Investigate cost of joining a gym. (Lynn, older sister)

Clearly, Emily and her family have embraced the concept of Person-Centered Planning. They are well aware of the advantages it has for creating the life Emily and her family wants.



Resources

Additional resources on Person-Centered Planning are listed below.

Books

A Good Life: For You and Your Relative with a Disability
by Al Etmansky. Burnaby, BC: Planned Lifetime Advocacy Network (PLAN).

A Little Book About Person Centered Planning: Ways to Think about Person-Centered Planning, its Limitations, and the Conditions for its Success
by John O'Brien & Connie Lyle O'Brien - Editors. Toronto, ON: Inclusion Press.

Implementing Person-Centered Planning: Voices of Experience
by John O'Brien & Connie Lyle O'Brien - Editors. Toronto, ON: Inclusion Press.

PATH: Planning Possible Positive Futures: Planning Alternative Tomorrows with Hope for Schools, Organizations, Businesses and Families
by Jack Pearpoint, John O'Brien, Marsha Forest. Toronto, ON: Inclusion Press.

All My Life's a Circle: Using the Tools: Circles, MAPS and PATH
by M. Falvey, M. Forest, J. Pearpoint, and R. Rosenberg. Toronto, ON: Inclusion Press.

Person-Centered Planning with MAPS and PATH: A Workbook for Facilitators
by John O'Brien & Jack Pearpoint. Toronto, ON: Inclusion Press.



Web Sites

www.inclusion.com – The home of Inclusion Press, this web site provides a source of books and videos as well as other resources on Person-Centered Planning.

iod.unh.edu/Self-Determination/publications1251/pcp.html – The article "Centering Our Planning on People," by Judith Snow may be found at this site (National Program Office on Self-Determination).

www.omr.state.ny.us/wt/manuals/mscvm/wt_1app1pcp.jsp – An overview of person-centered planning is provided on this web site. Of particular interest is the section "The Eight Hallmarks of Person-Centered Planning (with 23 indicators)."

www.paradigm-uk.org/articlespcp.html – This web site is a source of numerous articles on Person-Centered Planning.

www.qualitymall.org – This web site is a comprehensive source of information on person-centered supports for people with developmental disabilities.

www.pdd.org/Central/mylife/index.htm – This is the location of "My Life," a workbook produced by the Central Alberta PDD Community Board to help self-advocates plan their future.

www.nepdd.org – "Understanding Your Funding Options: A Guide for Families of Individuals with Developmental Disabilities" is a multimedia resource designed by the Northeast Alberta Community Board for Persons with Developmental Disabilities.



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Fax: **(780) 645-6229**

Our offices are open Monday to Friday from 8:15 am – 4:30 pm.
Our offices are fully accessible.

Web site: **www.nepdd.org**
Northeast Community Online: **www.ne-community.com**

Alberta Association for Community Living (AACL)

11724 Kingsway
Edmonton, Alberta T5G 0X5

Telephone: **(780) 451-3055**
Toll Free: **1-800-252-7556**
Fax: **(780) 453-5779**

E-mail: **mail@aacl.org**
Web site: **www.aacl.org**

Northeast Alberta AACL Family Voices Network and Community Councils

For information on how to contact these groups in your area,
contact your local PDD office or AACL.



Northeast Alberta Community Board Persons with Developmental Disabilities

Vision

An Alberta that honours and respects the dignity and equal worth of persons with developmental disabilities.

Mission Statement

To facilitate collaborative leadership with individuals and families in the creation, development, and support of community-based services, programs, and partnerships, which ensures the Board's vision in communities throughout Northeast Alberta.



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